

Clinical trials are the primary means of testing new therapies for serious diseases. In fact, these trials may be the only available treatment for patients whose conditions have failed to respond to conventional therapies.

The survey by the American Society of Clinical Oncologists discussed in the article found that less than five percent of cancer patients in the country are enrolled in clinical trials—although 20 percent are eligible to participate and would often receive better quality care if they did. As the article points out, “Patients who participate receive at least state-of-the-art treatment and often get to take advantage of otherwise unavailable approaches.”

Several barriers exist to enrolling patients in clinical trials. But a critical element is the increasing reluctance of HMOs and other managed care plans to allow their enrollees to participate in such trials or to pay the routine hospitals costs of their participation is a critical element. Until recently, health insurance routinely paid for the doctor and hospital costs associated with clinical trials. But managed care is reducing that commitment. Today, managed care plans often will not permit their patients to enroll in clinical trials, and they will not pay for their participation when they choose to do so on their own.

The American Association of Health Plans—the HMO trade association—has recognized that plans should encourage patients to participate in clinical trials, where medically appropriate. But, too often, there is little or no participation.

The decision to enter a clinical trial should be made by the treating physician and the patient. Yet the survey showed that only about half of eligible patients are even told such trials are available.

S. 6, the Patients’ Bill of Rights, and its companion bill, HR 358, require health insurance plans to allow their enrollees to participate in quality clinical trials sponsored by the NIH, the Department of Defense, and the Veterans Administration. The lack of access highlighted by the article clearly demonstrates the need for passage of the Patients’ Bill of Rights. Without the protections in that bill, patients will not be guaranteed the right to participate in these life-saving trials. Virtually every major cancer group in the nation has endorsed the Patients’ Bill of Rights, and highlighted the clinical trials provision as a major reason for enactment.

Patients are dying and cures of the future are being delayed. Patients deserve this opportunity for life. The rights guaranteed in the Patients’ Bill of Rights are essential for patients with cancer, congestive heart failure, lupus, Alzheimer’s Disease, Parkinson’s Disease, diabetes, and many other deadly illnesses. Every day we delay

more patients suffer. Congress has an obligation to act.

I ask unanimous consent that the article from the New York Times may be printed in the RECORD.

There being no objection, the article was ordered to be printed in the RECORD, as follows:

[From the New York Times, May 16, 1999]
FEW TAKE PART IN CANCER TESTS, SLOWING RESEARCH, SURVEY FINDS

ATLANTA, May 15 (AP).—Fewer than 5 percent of cancer patients in the nation take part in experiments to test new treatments, a figure at least four times lower than ideal if the most pressing cancer questions are to be answered quickly, according to a survey released today.

“We need clinical trials to know what works and what doesn’t,” said Dr. Allen Lichter, president of the American Society of Clinical Oncology.

Cancer experts almost universally endorse the need for patients to participate in formal studies, but data on how many do so have been scarce. So the oncology society, the nation’s largest group of cancer practitioners, commissioned a survey of about 7,000 of its members and released the results at its annual meeting here.

The survey found that about 40,000 Americans—3 percent to 5 percent of those found to have cancer each year—are enrolled in studies of the disease. Far more patients could take part in the experiments, which doctors call clinical trials, the study found.

The survey estimated that about 20 percent of cancer patients would be eligible to participate in the studies taking place of their kinds of conditions.

Dr. Ezekiel Emmanuel of the National Institutes of Health, the study’s primary author, said doctors should try to enroll the entire 20 percent.

The experiments typically test new medicines or combinations of drugs to see whether they work better than standard approaches. Patients who participate receive at least state-of-the-art treatment and often get to take advantage of otherwise unavailable approaches.

Only about half of eligible patients are told the studies are available. And only 20 percent of cancer specialists have time set aside to do this kind of cancer research.

The survey found that a doctor’s cost of enrolling and keeping a single patient in a clinical trial averages \$2,000.

The National Cancer Institute, the single largest sponsor of these studies, pays doctors \$750 a patient for this work, while pharmaceutical companies’ average payment is about \$2,500.

MESSAGES FROM THE PRESIDENT

Messages from the President of the United States were communicated to the Senate by Mr. Williams, one of his secretaries.

EXECUTIVE MESSAGES REFERRED

As in executive session the Presiding Officer laid before the Senate messages from the President of the United States submitting sundry nominations which were referred to the appropriate committees.

(The nominations received today are printed at the end of the Senate proceedings.)

NOTICE ON CONTINUATION OF EMERGENCY WITH RESPECT TO BURMA—MESSAGE FROM THE PRESIDENT—PM 29

The PRESIDING OFFICER laid before the Senate the following message from the President of the United States, together with an accompanying report; which was referred to the Committee on Banking, Housing, and Urban Affairs.

To the Congress of the United States:

Section 202(d) of the National Emergencies Act (50 U.S.C. 1622(d)) provides for the automatic termination of a national emergency unless, prior to the anniversary date of its declaration, the President publishes in the *Federal Register* and transmits to the Congress a notice stating that the emergency is to continue in effect beyond the anniversary date. In accordance with this provision, I have sent the enclosed notice to the *Federal Register* for publication, stating that the emergency declared with respect to Burma is to continue in effect beyond May 20, 1999.

As long as the Government of Burma continues its policies of committing large-scale repression of the democratic opposition in Burma, this situation continues to pose an unusual and extraordinary threat to the national security and foreign policy of the United States. For this reason, I have determined that it is necessary to maintain in force these emergency authorities beyond May 20, 1999.

WILLIAM J. CLINTON.

THE WHITE HOUSE, May 18, 1999.

MESSAGES FROM THE HOUSE

At 2:23 p.m., a message from the House of Representatives, delivered by Mr. Hays, one of its reading clerks, announced that the House has passed the following bill, in which it requests the concurrence of the Senate:

H.R. 1555. An act to authorize appropriations for fiscal year 200 for intelligence and intelligence-related activities of the United States Government, the Community Management Account, and the Central Intelligence Agency Retirement and Disability System, and for other purposes.

ENROLLED BILL SIGNED

The message also announced that the Speaker has signed the following enrolled bill:

H.R. 669. An act to amend the Peace Corps Act to authorize appropriations for fiscal years 2000 through 2003 to carry out that Act, and for other purposes.

The enrolled bill was signed subsequently by the President pro tempore (Mr. THURMOND).

MEASURE PLACED ON THE CALENDAR

The following bill was read the first and second times and placed on the calendar: